

Real Choices Considerations for HHS Regulation Development

Draft 1/9/2003 (content changes from 12/12 noted in **bold**)

(Changes from Consumer Task Force Meeting of August 30, 2004 highlighted gray with Italicized font)

This matrix is envisioned as a tool used by staff as they develop or revise regulations representing a wide variety of HHS programs. Consideration of the Real Choices principles would be required, but specific content would be applied as appropriate. Each program will continue to operate within set parameters, some of which will limit choices. The hope is that program parameters that are flexible will be designed to provide consumer choice. **In some cases, the “considerations” which support the Guiding Principle may not apply to development of a specific regulation, but rather to the overall “spirit” of program development and administration. Again, regulations and practices which reflect overall flexibility to allow and encourage consumer priorities will support the philosophy of real choices.**

GUIDING PRINCIPLES	CONSIDERATIONS	BEST PRACTICE	AVOID
Authority (and Freedom, regarding degree of family involvement)	CONSUMERS HAVE THE AUTHORITY TO - *Define/pursue own visions and dreams	<i>Consumers receive training & skills on defining & pursuing their visions & dreams & how to obtain them.</i> <i>Those practices being Independent Living Centers and Community Supports Project</i>	
	*Make decisions to control own lives	The consumer/family has the authority to direct the service plan (Individualized Family Services Plan in Early Intervention)	<i>Decisions made by a team</i>
	<i>*Authority of amount of family involvement</i>	Adult consumers decide who is family to be included/excluded Exception: Legal guardianship Note: "Family" is not legally defined Note: This does not change a program's definition of "family" for eligibility purposes	<i>Assuming the Western Anglo family traditions and roles</i> <i>"Power" chair arrangement & environmental & attitudinal barriers in meetings which diminish consumers importance</i>

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Authority continued	<i>Authority of amount of family involvement (cont)</i>	Consumers determine priority based on program's maximum benefit available (monthly "cap" in Aged and Disabled Waiver)	Pre-printed, standard plan format
	*Control & direct financial resources, services & supports	Friendly-format benefits such as electronic benefit cards in Food Stamps or bus token like used by general public	<i>Pre-determined methods of selection of services, supports & resources such as specialized providers in the DD Waiver</i> <i>Habilitation being tied to the provision of services & support</i>
Freedom	CONSUMERS HAVE THE FREEDOM TO - *Express needs/preferences <i>Consumer/Family receives information on principles, roles & general information from their chosen credible messenger</i>	Consistency in information/mediation processes for grievances, disputes, complaints	Pre-determined or inflexible communicator/messengers, i.e., or such as DD Service Coordinators being predefined, preset communicators.
	*Plan their lives with culturally appropriate informal & formal supports	Translation available in <i>accessible materials (i.e. information, brochures, resources, regulations, forms)</i>	Single format materials
		Staff who are bi-lingual	Excluding culturally-defined decision-makers

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Freedom (cont)	Plan their lives with culturally appropriate informal & formal supports (cont)	<i>Provide</i> access to interpreters or resources (<i>i.e., manual, language</i>)	
		Recognize cultural influences in defining "family" according to the consumer's definition	Expectations that family member will always serve as interpreters
		Provide services in cultural community settings	
	*Take risks & learn from their choices	Consumers (in the absence of legal guardianship) have the right to determine their risk (Kansas-HCBS philosophy)	Labels that relate to ability to take risk, such as age or disability
		Person-centered planning (national effort)	Plans too complex for real <i>meaningful</i> implementation
		<i>Provide</i> full information for informed choice (provide information on medication side effects and interactions so benefits & risks can both be considered; <i>cancer treatment</i>)	<i>Decisions based on "non-compliance" only</i> <i>Services dependent on level of compliance</i>

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Freedom (cont)	*Promote positive change to service delivery & public policy	Promote practices to encourage consumer input on policy changes & the ongoing program. Share proposed changes with advocacy groups. (Examples: NE's 1997 Long Term Care Plan. VA's Town Hall Webpage for regulation proposals)	Including only providers (and others with financial interest) when obtaining public input
		Assure no negative repercussions toward consumers (and that consumers are assured of this)	
Responsibility	<p>CONSUMERS HAVE THE RESPONSIBILITY TO-</p> <p>*Monitor & evaluate the quality of their services</p> <p><i>(How do we inform the consumers what their choices are & how are we supporting people to be self-informed choice makers?)</i></p>	<p>Provider profile (ARC)</p> <p>Support consumers to hire & direct their own service providers (Independent Living Center philosophy-League of Human Dignity</p> <p><i>Develop an interviewing tool/sheet to help consumers with interviewing skills</i></p>	

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Responsibility (cont)	<p>*Self-advocate</p> <p><i>Are there opportunities to link specific consumers with credible messengers, other links with peers linkage - people bringing information to those with disabilities if they need help in directing their services or to advocate for them</i></p>	<p>Include Rights & Responsibilities list in regulation</p> <p>Operate program with expectation that consumers have an input role; consumers encouraged to identify needs/priorities</p> <p><i>Input of a broader advocacy constituencies of whether its in the actual first development of regulations as well as with things like monitoring & advocating for individuals with disabilities</i></p> <p><i>A process where regulations are read through, identified advocacy constituencies for that particular disability category.</i></p>	<p>"Hiding" the rights & responsibilities. Share information with explanation, brochures, etc.</p>
	<p>*Make best use of public dollars in life-enhancing ways</p>	<p>Priorities are identified by consumers</p> <p>Clear description of program & consumer roles</p> <ul style="list-style-type: none"> • Opportunities • Expectations <p>(i.e., wrap around services, contracts, written plans)</p>	

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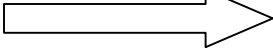
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Support	CONSUMERS HAVE THE NECESSARY SUPPORTS TO- *Live & work in their community	Support community inclusion Provide service in accessible locations, encouraging flexible alternatives to meet individual needs (i.e., fair hearings by telephone)	"Homebound" requirements; defined or limited settings for service delivery
	*Live their lives based on informed choices	Included in Rights, informed decision makers <i>Information inputs for consumers and sheets with bullet points on regulations</i>	
Rights	CONSUMERS HAVE THE RIGHT TO- *Receive culturally-competent services	Included under Freedom	
	*Be respected, valued community members, supported in their relationships	Included under Freedom	
	*Be informed & empowered decision makers	Support consistency in applying regulations by providing a guide for users that includes both formal policy & process/training guidance (Aged & Disabled Waiver)	

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Rights (cont)	Be informed & empowered decision makers (cont)	Program provides all information available & supports access to specialized resources for other information (ARC,NRRS, Mother-to Mother at Chicano Awareness)	Filtering information provided, based on program bias Concentrating only on the worker's assigned program & its "menu"
		Program & consumer are partners	
	Did not know where group 2 wanted to have these 2 items placed 	<i>Ensure there are choices in environments where all services for everyone who needs them are available and DO take place</i> <i>Monitoring continuous improvement in transparency - continuous improvement in a real database viewpoint</i>	
	*Direct & manage own services/supports, if they choose	Included under Freedom	
	*Engage in meaningful work	<i>Workforce Development Assessment to look at skills in an area, value & interests in a career or activity</i> <i>Overall evaluation of program eligibility & how it affects a person's access to service</i>	Personal caring services (where they are limited to provision in the home) SSDI Letters (don't work too much or you'll lose your benefits)

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Personal caring services

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Rights (cont)	Engage in meaningful work (cont)	<i>Program implementation include a thorough Benefits Analysis for an individual (i.e., consumer & family are aware of financial implications on benefits may lose SSI or food stamps)</i>	
	*Receive high quality, cost effective services & supports	Provider standards which address basic protections without unnecessary limits. Have minimum standards, which balance higher quality with consumer choice (Risk Management allows transportation providers to have some points against their drivers licenses)	
	*Have personal security & well-being without sacrificing rights	<i>Recognize the right risk depending on person's cognitive abilities (would require assessment of intellectual, mental & physical capabilities then appropriate communication to the individual information they need to know what decision it is that they need to be making Ongoing QA for services, provider based services (1 to 1 interviews & follow up on issues identified in the interviews)</i>	

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Rights (cont)	Have personal security & well-being without sacrificing rights (cont)	<i>The right to confidentiality</i> <i>The right for proper informed communication</i>	
Application Process	*Consumer input on sharing information	Common application form (disabled persons & family support) <i>Insure that the consumer is the primary source of information where possible</i>	Mailing complex applications
Writing Style	*People First Language	<i>Make regulations available in appropriate languages</i>	
	*Alternate communication methods such as Braille, recording		
	*Simple, easy to understand, plain language		Bureaucrat speak when a common term or simple sentence can cover the content
Services	*Consistent Terms	RAID developing internal database of policy definitions <i>Use box texted annotations to explain the meaning</i>	<i>Terminology as blind and disabled (separate the blind from disability)</i> <i>Terminology in statute</i> <i>Inform & feeble</i>